

**Department of Health and Human Services**

**OFFICE OF  
INSPECTOR GENERAL**

**Problems Pervade the Renal Beneficiary  
and Utilization System**



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# EXECUTIVE SUMMARY

## PURPOSE

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To describe the state of the Renal Beneficiary and Utilization System and to evaluate how the system and resulting data are used.

## BACKGROUND

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End Stage Renal Disease (ESRD), characterized by a permanent loss of kidney function, is the only basis for entitlement to Medicare based on the presence of a specific medical diagnosis. The ESRD beneficiaries are entitled to full Medicare benefits as well as the services Congress specifically allows for these beneficiaries (e.g., dialysis, transplant procedures, selected pharmaceuticals, and nutrition supplies). At the end of 1999, the ESRD population in the United States had climbed to approximately 329,000, with Medicare expenditures of \$11.3 billion. In the next 10 years, the number of individuals with ESRD, as well as Medicare expenditures, is projected to double.

The Centers for Medicare & Medicaid Services (CMS) is charged with the administration of the ESRD Program. Within CMS, the Information Systems Group manages the operation of the legislatively mandated system covering medical and demographic information for the Medicare ESRD population, the Renal Beneficiary and Utilization System (REBUS).

The REBUS is intended to serve as a source of ESRD information, consolidated from various data providers. The main function of REBUS is to maintain data used in the determination of Medicare entitlement, including disenrollment, death, transplant, and dialysis treatment data. The REBUS also supports program analysis, policy development, program operations, and epidemiologic research. We were alerted to problems with REBUS when we experienced complications attempting to access data from the system for another inspection. Given the critical nature of the system, we examined the status of REBUS and evaluated the effects that data and communication problems have on data providers and end users.

## FINDINGS

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### **Datasets Within the Renal Beneficiary and Utilization System are Out-of-date, Incomplete, and Inaccurate**

Problems existed with 9 of the 12 REBUS datasets within the 12 months prior to the completion of our fieldwork (August 2001). Although CMS has taken steps to update some datasets, problems continue. The most common problem with REBUS datasets is that they are out-of-date, thus leading to incomplete and inaccurate data.

## **Data Problems Result in Duplication of Effort, Delays, and Program Vulnerabilities**

Due to data problems with REBUS, some groups are requesting data already provided to CMS directly from the data providers. Representatives from the United States Renal Data System (USRDS) reported that their 2001 annual report, which presents national ESRD data, was delayed due to shortcomings in the REBUS data. Representatives from both CMS and the USRDS stated that when the dataset regarding Transplant Follow-up was not current, CMS did not have the information needed to terminate beneficiaries who had undergone successful transplants, thus resulting in an estimated 50,000 individuals continuing to receive Medicare benefits beyond their period of eligibility. In addition, incomplete Patient Status data has led to termination of ESRD benefits for beneficiaries enrolled in managed care plans.

## **Data Problems are the Result of Historical Complications, a Lack of Resources, and an Outdated Database**

Data problems have plagued the ESRD Program since its inception in 1973. The CMS has reorganized several times, resulting in changes in the components responsible for operation and oversight of REBUS. During these reorganizations, key staff members were reassigned, including the two original architects of REBUS. In addition, the REBUS uses an outdated programming language, and there are few programmers who have the expertise to work with such a system. Due to its age and programming language, REBUS is incompatible with the modernized systems with which it is supposed to exchange data.

## **Lack of Defined Roles and Relationships Leads to Poor Communication**

Representatives from the primary organizations providing data for or using data from REBUS (e.g., the ESRD Networks, United Network for Organ Sharing, and the United States Renal Data System) noted long standing communication problems with CMS. Representatives said that few meetings are held to discuss data quality issues. The CMS representatives agreed that communication with some groups may be lacking.

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## **RECOMMENDATIONS**

The CMS is well aware of problems within REBUS. The CMS has expended considerable effort maintaining and updating REBUS, and steps have been underway for some time to develop a replacement system. Considering the history of data problems with REBUS and the various delays that have stalled the implementation of the replacement system, we recommend that CMS:

### **Develop a Strategic Plan for Addressing ESRD Data Management**

The strategic plan should build on CMS's current efforts to address data shortcomings. At a minimum, the plan should address the following four areas:

▶ **Short and Long-Term Targets**

The CMS's strategic plan should address target dates for updating REBUS and restoring out-of-date datasets. In addition, the plan should establish realistic target dates for the completion of the replacement system and the transfer of data from REBUS into this system.

▶ **Data Needs**

Problems with the timeliness, completeness, and accuracy of some datasets within REBUS raise questions as to the importance of these datasets to the operation of CMS's ESRD program. The CMS should assess internal data needs and the needs of external data users to determine the appropriateness of CMS maintaining these data.

▶ **Efficiency of Data Distribution**

Within the constraints of the Privacy Act and other applicable laws and regulations, CMS should reassess where and how ESRD users obtain needed data. If CMS decides that it is most appropriate for end users to obtain data directly from the source, it should factor in this decision when determining which datasets should be retained.

▶ **On-going Communication**

The CMS should establish regular, periodic meetings to discuss ESRD data management issues with internal and external data providers and end users.

## **Coordinate with the Social Security Administration to Address Errors in Basic Beneficiary Information**

According to CMS representatives, SSA has given low priority to correcting errors in ESRD beneficiary records. The CMS may want to consider holding high-level meetings with SSA to develop a mutually acceptable solution for addressing problems with basic beneficiary information.

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## **AGENCY COMMENTS**

In its written response to our report, CMS acknowledged limitations with REBUS and concurred with our recommendations. The CMS highlighted various actions taken since completion of our draft report, including devising short and long-term strategic plans, initiating meetings with data providers and users, and reaching agreements to reduce or eliminate non-essential data transfers. In addition, CMS is now encouraging various data users to seek information directly from the source rather than relying on CMS's system.

We made minor changes to reflect technical comments received from CMS. The full text of CMS's comments are included in Appendix A.

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# INTRODUCTION

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## PURPOSE

To describe the state of the Renal Beneficiary and Utilization System and to evaluate how the system and resulting data are used.

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## BACKGROUND

This inspection topic stems from complications faced while attempting to access data from the Renal Beneficiary and Utilization System (REBUS), the critical End Stage Renal Disease (ESRD) data system, for the planned inspection entitled “End Stage Renal Disease: Method Election Vulnerabilities.” Efforts to select a universe of beneficiaries for that inspection were compromised by problems encountered with a particular dataset within REBUS. Inquiries to the Centers for Medicare & Medicaid Services (CMS) revealed that some datasets in REBUS had not been updated in more than 2 years. Concerns about the entire data system developed as we were informed that data in other datasets may have been similarly out-of-date and incomplete.

### End Stage Renal Disease

End Stage Renal Disease is characterized by a permanent and irreversible loss of kidney function requiring either kidney transplantation or regular dialysis treatments in order to survive. In 1972, amendments to Title XVIII of the Social Security Act extended Medicare Part A and Part B benefits to virtually all individuals with ESRD regardless of age.<sup>1</sup> The ESRD program is the only Medicare program for which entitlement is based on the presence of a specific medical diagnosis.

The ESRD beneficiaries are entitled to full Medicare benefits as well as services Congress specifically allows for these beneficiaries (e.g., dialysis, transplant procedures, selected pharmaceuticals, and nutrition supplies). In 1973, the year in which the program was initiated, the number of eligible ESRD beneficiaries totaled 10,000. By the end of 1999, the ESRD population in the United States had climbed to approximately 329,000, with Medicare expenditures of \$11.3 billion.<sup>2</sup> The number of individuals with ESRD is

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<sup>1</sup> Individuals who suffer from ESRD and are under age 65 may experience a 3-month waiting period prior to Medicare coverage. In addition, individuals who have coverage under an Employer’s Group Health Plan may undergo a 30-month period in which Medicare acts as a secondary payer to the Group Health Plan.

<sup>2</sup> United States Renal Data System, retrieved from the World Wide Web: <http://www.usrds.org/atlas.htm> (August 30, 2001).

projected to double by 2010, surpassing 660,000 individuals, with projected Medicare expenditures in excess of \$28 billion.<sup>3</sup>

The CMS is charged with the administration of Medicare benefits to eligible persons with ESRD. Integral to the effective administration and management of this program is the effective operation of REBUS, the comprehensive database covering medical and demographic information for the Medicare ESRD population.

## **ESRD Information System**

In 1978, Public Law 95-292, section (c)(1)(A), mandated the Secretary of the Department of Health, Education and Welfare to establish a renal disease medical information system. This legislation stemmed from the need to calculate utilization rates and serve the administrative needs of the expanding program. The resulting system merged data from an existing patient dialysis registry, a transplant registry, and Medicare eligibility and claims data from the Social Security Administration (SSA).

The technical design and operation of this data merger proved difficult. An agency report from the then Health Care Financing Administration noted that poor contract management, inter-office miscommunication, and staff turnover slowed the implementation of the system.<sup>4</sup> After an internal reorganization, the ESRD program staff began publishing the first series of regular reports using the ESRD medical information system in mid-1979. The system was fully operational by July 1980.

## **The Renal Beneficiary and Utilization System**

The REBUS is the interactive tool used to access data within the Program Management and Medical Information System, the actual repository for the ESRD program data. This repository contains data covering the medical and demographic information for the ESRD population. Both CMS and the end users of data commonly refer to both the tool and the repository as REBUS, as will we throughout this report. The main function of REBUS is to maintain data used in the determination of Medicare ESRD entitlement, including disenrollment, death, transplant, and dialysis treatment data. The REBUS also supports program analysis, policy development, program operations, and epidemiologic research.

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<sup>3</sup> United States Renal Data System, retrieved from the World Wide Web: [http://www.usrds.org/atlas\\_2000.htm](http://www.usrds.org/atlas_2000.htm) (August 30, 2001).

<sup>4</sup> "Implementing the End Stage Renal Program of Medicare," Richard Rettig, R-2505 HCFA/HEW, September 1980.

The CMS describes REBUS as:

... a mission critical system that is used by CMS and the renal community to perform their duties and responsibilities in monitoring the Medicare status, transplant activities, dialysis activities, and Medicare utilization (inpatient and physician-supplier bills) of ESRD patients and their Medicare providers, as well as in calculating the Medicare-covered period of ESRD.

The REBUS data are used for payment decisions and actuarial projections, as well as serving the needs of the research and planning divisions within CMS, including the Center for Beneficiary Choices, the Office of Clinical Standards and Quality, The Center for Medicaid and State Operations, and the Office of Strategic Planning.

## REBUS Structure

The REBUS is composed of twelve datasets. The information contained within those datasets is derived from data exchanges between groups as indicated below. The providers for this data are further described on the following page.

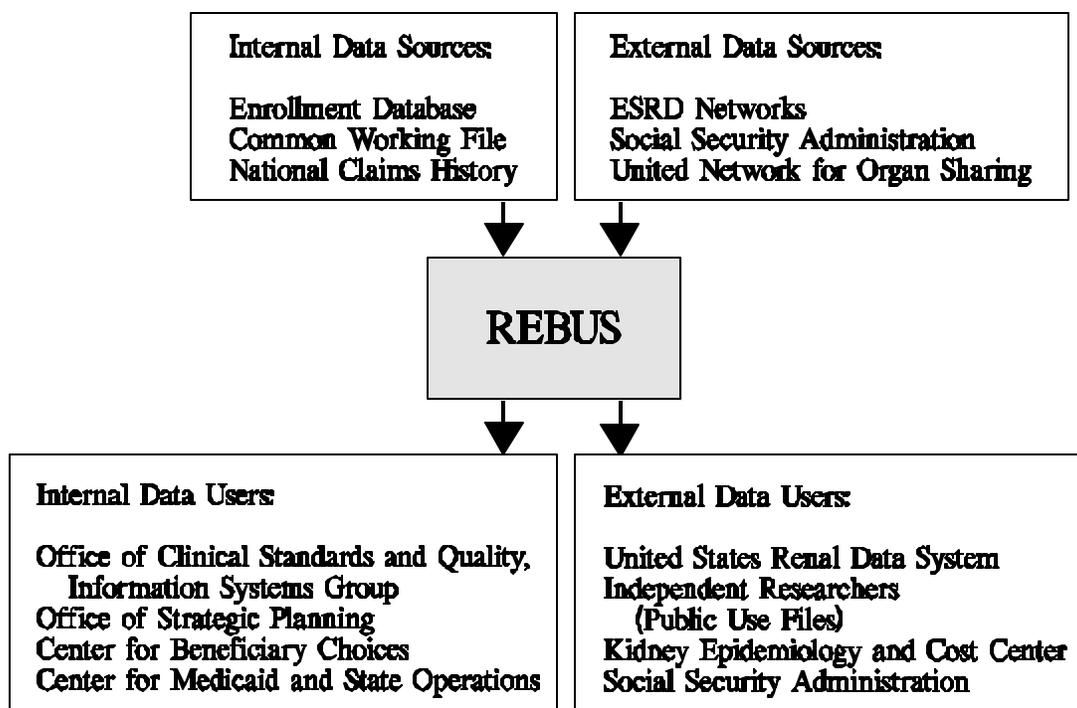
<b>Dataset</b>	<b>Data Description</b>	<b>Data Source</b>
<b>Death Notice</b>	Date, place, and cause of death	ESRD Networks
<b>Facility Certification</b>	Annual provider-specific treatment and transplant data	ESRD Networks
<b>Identification</b>	Basic beneficiary, entitlement, and ESRD termination data	Social Security Administration
<b>Inpatient Stay</b>	Hospital stay dates, provider number, surgery information	National Claims History
<b>Medical Evidence</b>	Medical conditions, lab results	ESRD Networks
<b>Method Selection</b>	ESRD payment method chosen by home dialysis patients	Common Working File
<b>Patient Status</b>	Verified renal status, dialysis type, most recent treatment setting	ESRD Networks
<b>Quarterly Dialysis</b>	Aggregated information for all dialysis claims in the quarter	National Claims History
<b>SSA District Office</b>	Addresses of local Social Security Administration offices	Social Security Administration
<b>Transplant</b>	Date of transplant; organ donor data	United Network for Organ Sharing
<b>Transplant Follow-up</b>	Tracks the status of the beneficiaries transplant	United Network for Organ Sharing
<b>Wait List</b>	Potential kidney transplant recipients awaiting transplantation	United Network for Organ Sharing

Source: CMS Data Users Guide

## REBUS Data Exchanges and Usage

The REBUS data mostly are created and maintained in other systems, and then periodically uploaded into REBUS. Below are descriptions of the various data providers for REBUS, followed by descriptions of common users of REBUS. The primary sources of data for REBUS and the users of the resulting REBUS data are illustrated below in Diagram 1. A discussion of the data sources and external data users follows the diagram.

**Diagram 1: REBUS Data Providers and Users**



### Data Providers (Internal)

*Enrollment Database* -- This database contains information on all Medicare beneficiaries from the beginning of the Medicare program in 1966 to the present.

*Common Working File* -- Fiscal intermediaries and carriers, which work under contract for CMS, use the Common Working File to process claims. The file contains edits to screen claims, helping to ensure proper claims processing. These edits, for example, would help ensure that ESRD-related claims are supported by a diagnosis of ESRD for the beneficiary or that the type of treatment being claimed corresponds with the method of treatment the beneficiary selected.

*National Claims History* -- This file serves as a single repository for both Medicare Part A and Part B claims, which would include 100 percent of ESRD claims. The National

Claims History contains every claim submitted since 1991 along with all adjustment claims.

## **Data Providers (External)**

*ESRD Networks* -- In 1987, Congress mandated the formation of 18 ESRD Networks to assist in the collection and verification of patient, facility, and provider data. Dialysis treatment facilities complete required HCFA forms, including the HCFA-2728 Medical Evidence, HCFA-2746 Death Notification, and HCFA-2744 Annual Facility Survey. These forms are then forwarded to the regional Networks for data entry into the Standard Information Management System (SIMS), an electronic database implemented in January 2000. This system enables all 18 Networks to maintain uniform beneficiary and provider data from their respective regions, which are to be periodically uploaded into REBUS.

*Social Security Administration* -- The primary source for beneficiary information in CMS's Enrollment Database is SSA, which supplies information for updating the database daily.

*The United Network for Organ Sharing (UNOS)* -- The UNOS maintains the nation's organ transplant wait list under contract with the Health Resources and Services Administration (HRSA). This data is instrumental in developing organ transplantation policy as well as maintaining effective operation of the Organ Procurement and Transplantation Network. The Network maintains a national electronic list of patients waiting for organ transplantation and is responsible for matching donors and recipients. The UNOS sends their data to CMS, which is then loaded into REBUS. The data includes information regarding the donor and recipient, the date of the organ transplant, and routine follow-up information on the patient and transplanted kidney.

## **Data Users (External)**

*United States Renal Data System (USRDS)* -- In 1986, Public Law 99-509 mandated the establishment of a national ESRD patient registry. This registry, the USRDS, formerly operated through the University of Michigan and currently operates through the Minneapolis Medical Research Foundation, University of Minnesota Twin Cities under contract with the National Institutes of Health. The USRDS relies on REBUS as its major source of data on the incidence and prevalence of kidney failure, the rates of hospitalization and transplantation, the rates and causes of death, and the costs of associated medical care. The USRDS distributes information to Congress, several Federal agencies, and the ESRD community through its annual reports.

*Independent Researchers* -- The CMS creates Public Use Files used for independent and organizational research. The REBUS has been used in a number of ways, including basic descriptive epidemiology, analysis of mortality rates, and assessments of programmatic issues, such as reimbursement and clinical practice.

*University of Michigan Kidney Epidemiology and Cost Center (KECC)* -- The Center uses data from REBUS to create facility specific reports for facilities, Networks, and state agencies. The Center also creates state specific reports which are used in program operations and oversight.

*Social Security Administration* -- The SSA receives ESRD termination data from REBUS so that it can correctly terminate beneficiaries as their entitlement expires.

## **The Renal Management Information System (REMIS)**

The CMS is developing a modernized information system to replace REBUS. The replacement, REMIS, is expected to improve system access and data quality because it will integrate better with updated systems of internal and external data providers. Plans for the development of REMIS were announced in December 1999, with the implementation date originally set for Spring 2000. Due to delays in the development of REMIS, the current target date is Spring 2002.

## **Other ESRD Work by the Office of Inspector General**

The Office of Inspector General (OIG) has issued several ESRD-related studies. Most recently, the OIG released "External Quality Review of Dialysis Facilities: A Call for Greater Accountability," OEI-01-99-00050, June 2000. The study found that CMS does not require a core set of facility-specific clinical performance measures, limiting its ability in identifying poorly performing facilities. The study also found deficiencies in lines of communication between the Networks and State agencies.

In January 2001, the OIG issued "Review of Separately Billed End Stage Renal Disease Hospital Outpatient Laboratory Tests Included in the Composite Rate," A-01-99-00506, a follow-up to the October 1996 report, "Review of Separately Billable ESRD Laboratory Tests," A-01-96-00513. Both reports found that hospital laboratories were reimbursed separately for laboratory services already included in the dialysis facility's composite rate. Based on a statistical sample, the 2001 report estimated that \$6.1 million was improperly paid to hospital laboratories for services provided to ESRD beneficiaries during calendar years 1995 through 1997.

The OIG also released three reports focusing on the appropriateness of payments to Health Maintenance Organizations for ESRD-classified beneficiaries. In February 1996, the OIG issued "Review of Medicare Payments to Health Maintenance Organizations for End Stage Renal Disease Beneficiaries," A-04-94-01090. Later the OIG released "End Stage Renal Disease Payments to Health Maintenance Organizations (HMOs)," A-14-9600203, June 1997, and "Review of HMO Payments-Beneficiaries on Dialysis," A-14-98-00211, July 2000. In each of these reports, the OIG found significant overpayments to HMOs for Medicare beneficiaries inappropriately identified as having ESRD due to the enhanced rate received for patients in that high-cost category.

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## METHODOLOGY

As previously stated, this inspection was an outgrowth of complications faced while attempting to access data from REBUS for a planned inspection. Based on the data problems we identified through our initial inquiry, we gathered additional information from key stakeholders, including the Information Systems Group within CMS's Office of Clinical Standards and Quality, the ESRD Networks, UNOS, USRDS, and KECC. We were able to identify these key stakeholders through a CMS issued Data Users Guide which described each dataset of REBUS and how the information was exchanged between REBUS and stakeholders.

Using structured discussion guides, we collected from the Information Systems Group information about the concept and design of REBUS, the causes of current and prior data problems, and the phase-in plans for REMIS. We collected from external data providers (e.g., UNOS) and data users (e.g., USRDS) their experiences working with REBUS and CMS, the challenges they faced accessing and/or submitting data to REBUS, the effect data and system problems have had on their operations, and the steps they have taken to overcome these problems.

We analyzed all collected information, comparing the collective experiences of data providers, CMS, and data users, along with our own experiences. Our inspection focus was to assess the status of the individual REBUS datasets and how problems impact upon the data providers and users of the system. We did not test data within REBUS for completeness or accuracy because it was not our intent to assess the magnitude of problems so much as to assess the nature of the problems.

We conducted follow-up interviews with CMS regarding the status of REBUS datasets and any plans for updating these datasets as a final step in our fieldwork. Therefore, all statements related to status and update plans are current as of August 2001.

We conducted this inspection in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

# FINDINGS

## Datasets Within the Renal Beneficiary and Utilization System are Out-of-date, Incomplete, and Inaccurate

Problems existed with 9 of the 12 REBUS datasets within the 12 months prior to our fieldwork completion (August 2001). The table below provides the status of all REBUS datasets as of August 2001, followed by discussions of problems with selected datasets.<sup>5</sup>

**Table 2: REBUS Dataset Status**

Dataset	Description	Status	Plans for updating
<b>Death Notice</b>	Date, place, and cause of death	Current	N/A
<b>Facility Certification</b>	Annual provider-specific treatment and transplant data	Current	N/A
<b>Identification</b>	Basic beneficiary information, entitlement and ESRD termination data	Not Current	Dependent on other datasets
<b>Inpatient Stay</b>	Hospital stay dates, provider number, surgery information	Not Current	Up-to-date within 1 month
<b>Medical Evidence</b>	Medical conditions, lab results	Current	N/A
<b>Method Selection</b>	ESRD payment method chosen by home dialysis patients	Not Current	Data needs to be uploaded
<b>Patient Status</b>	Verified status, dialysis type, most recent treatment setting	Not Current	Up-to-date within 3 months
<b>Quarterly Dialysis</b>	Aggregated information for all dialysis claims in quarter	Current <sup>6</sup>	N/A
<b>SSA District Office</b>	Address of local SSA offices	Not Current	No plans to update
<b>Transplant</b>	Date of transplant, organ donor data	Current <sup>6</sup>	N/A
<b>Transplant Follow-up</b>	Tracks status of beneficiary transplant	Current <sup>6</sup>	N/A
<b>Wait List</b>	Potential kidney transplant recipients awaiting transplant	Not Current	Up-to-date within 3 months

<sup>5</sup> The status of REBUS datasets as of December 21, 2001, as reported by CMS, is included in Appendix A.

<sup>6</sup> These datasets were out-of-date during the prior 12-month period.

## **The Method Selection dataset is more than 2 years out-of-date**

We found that the Method Selection dataset, which indicates the payment method and the source of dialysis supplies for home dialysis beneficiaries, was more than 2 years out-of-date at the time of this review. We initially identified problems with this dataset when we attempted to select a universe of beneficiaries for the “End Stage Renal Disease: Method Election Vulnerabilities” inspection. The CMS representatives reported that, although they have since collected the historical data needed to update the dataset, they have yet to upload the data to bring the dataset up-to-date. Therefore, in order to obtain the method selection data needed for the aforementioned inspection, we have requested data directly from the Common Working File, which supplies REBUS with this data.

## **Systems incompatibility with the United Network for Organ Sharing has led to out-of-date and incomplete transplant data in REBUS**

The three datasets pertaining to organ transplantation (Transplant, Transplant Follow-up, and Wait List) are further examples of datasets which are out-of-date, leading to incomplete data. In January 2000, UNOS changed both the layout within their database and the method they use to submit data. The CMS was unable to upload this reformatted data into REBUS, which led to the datasets becoming out-of-date. After rewriting the process of accepting the UNOS data, CMS has reported they are now posting data to the Transplant and Transplant Follow-up datasets in a timely manner; however, problems still remain with the Wait List dataset. Because Medicare beneficiaries with successful transplants are limited by law to 36 months of post-operative coverage, the data UNOS supplies are essential for determining continued Medicare eligibility for patients with transplants.

## **Incomplete Patient Status data in REBUS may lead to termination of ESRD beneficiaries enrolled in managed care plans**

Representatives from the CMS regional offices alerted us to the potential of ESRD beneficiaries enrolled in managed care plans having their benefits inadvertently terminated because of incomplete data in the Patient Status dataset. The CMS relies on automated systems to determine the continued eligibility of ESRD beneficiaries. These systems rely on both claims activity (an estimated 15 percent of the Medicare ESRD beneficiaries are enrolled in managed care plans, meaning that these beneficiaries do not have individual dialysis claims filed for their treatments) and Patient Status data. The CMS formerly relied on the Networks’ bi-annual facility census to verify the status of patients. However, with the implementation of SIMS, the Networks no longer send this information. The REBUS is supposed to load the information continuously from SIMS, but the system is incompatible with SIMS and is unable to upload information directly. Therefore, patient status information in REBUS remains incomplete. Managed care beneficiaries run the risk of incorrect termination of benefits because CMS will terminate eligibility after 12 months of no claims activity and no update in Patient Status information.

## **Basic patient information in the Identification dataset is inaccurate**

The Networks, CMS, and USRDS all acknowledged problems with data in the Identification dataset. Information for this dataset is uploaded daily into REBUS based on information received from SSA. The ESRD Networks also maintain beneficiary identification information derived from the facility and patient forms. For several years, the SSA and Network data have not matched. During this time, CMS generated reports of non-matching data and sent these to both SSA and the Networks for verification or correction, as appropriate. The CMS officials reported that they have held discussions with various components within SSA regarding data errors. In addition, the Networks have and continue to report that they find their information is correct. Because the information in the Identification dataset is overwritten nightly based on information received from the SSA Master Beneficiary Record, it is not possible to correct the information in the Identification dataset permanently unless the SSA corrects its data. The SSA acknowledges that data corrections are a low priority unless the data directly effects beneficiary benefits and so data problems remain unresolved.

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## **Data Problems Result in Duplication of Effort, Delays, and Program Vulnerabilities**

We found that problems with REBUS data have created complications for data users. For example, CMS requires the ESRD Networks to produce annual reports. Sections of these reports are based on transplant information. As previously stated, transplant data from UNOS was, for a time, not loaded into REBUS. The Networks had to request the information directly from UNOS to complete their annual reports, which resulted in UNOS producing the same data twice. In addition, UNOS representatives reported that such work results in additional charges to the HRSA-administered contract.

The USRDS reported that its 2001 annual report was delayed due to shortcomings in the REBUS data. Representatives stated that some of the datasets they received had not been updated for some time. Because of outdated datasets, the USRDS had to obtain information, which should have been maintained in REBUS, from other sources to supplement the missing or incomplete data.

Moreover, problems with specific datasets in REBUS have created program vulnerabilities. The CMS reported delays in updating the Transplant Follow-up dataset, which tracks ESRD Medicare beneficiaries after transplantation. Beneficiaries who have undergone a kidney transplant are eligible for Medicare benefits for a statutorily set period of 36 months. If the transplant is successful, coverage should be terminated after the 36-month period. Representatives from both CMS and USRDS estimate that past problems with updating the Transplant Follow-up dataset has allowed an estimated 50,000 individuals with successful transplants to continue receiving Medicare benefits beyond their period of eligibility. Now that the Transplant Follow-up dataset is current, CMS representatives report that ESRD beneficiaries with successful transplants are being terminated properly. (The CMS

representatives stated that their plans are to retroactively adjust all individuals no longer entitled to Medicare due to successful transplants coverage, but not to collect any lost funds.)

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## **Data Problems are the Result of Historical Complications, a Lack of Resources, and an Outdated Database**

Data problems have plagued the ESRD Program since its inception in 1973. As previously stated, CMS experienced problems in the development of the original ESRD data system. While REBUS has centralized much of the data, many of the earlier identified problems remain. For example, in a report to the Secretary of Health, Education and Welfare in 1980, the history of the original ESRD system is described:

. . . at no time in the design, development, or operation of the system was sustained, informed policy direction given to the system. Consequently, issues of feasibility, need, and cost either went unanalyzed or were poorly investigated. [There was no] sufficient authority or power to give policy leadership . . . furthermore, familiar problems of the existing Medicare system nourished a belief that a new system could be created which would avoid these problems and that awarding an external contract was the means to this end.<sup>7</sup>

Although this is a description of the complications faced from 1973 to 1979, many of the problems are similar to those CMS currently experiences. The plan for the transfer to REMIS was first announced in the “Information Technology Architecture Sketches” newsletter in July 1999, with plans for implementation by Spring 2000. Two years later, the transfer still has not occurred.

The CMS cited various reasons for this delay. In 1997, CMS undertook an agency-wide reorganization, which resulted in the operation and oversight of REBUS moving from the Office of Information Systems to the Office of Clinical Standards and Quality. In this move, several crucial staff members were reassigned, including the two original architects of REBUS. Since this time, there have been numerous staffing changes, with new members frequently lacking experience in the ESRD program. Continuous staffing turnover and general lack of expertise have contributed to data problems.

The CMS has made efforts to address some of these shortcomings. The agency has re-hired one of the original architects of REBUS and has contracted with a private company to develop REMIS.

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<sup>7</sup> “Implementing the End Stage Renal Program of Medicare,” Richard Rettig, R-2505-HCFA/HEW, September 1980.

## **Obsolete technology renders REBUS incompatible with other systems and makes the system difficult to maintain**

The REBUS was created in 1980 to run as a mainframe application. Now, more than 20 years later, individuals with whom we spoke noted problems with the age of the system, its incompatibility with other systems, and the difficulty of finding programmers who know the programming language used to create the system. Each of these hinders CMS's ability to keep data within the system up-to-date.

The CMS has had to take special steps to allow data to be updated from several sources. Staff reported the three datasets they have been able to fix (Quarterly Dialysis, Transplant, and Transplant Follow-up) have all taken extra effort, such as rewriting the program and manual uploading. Staff also stated that the remaining five datasets plan to be up-to-date by the end of calendar year 2001. It is unclear, given competing priorities, if CMS will meet these target dates.

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## **Lack of Defined Roles and Relationships Leads to Poor Communication**

Despite CMS's reliance on external providers for REBUS data, representatives from each of the external groups with whom we spoke cited long standing communication problems with CMS. For example, even though UNOS is a major supplier of data and USRDS is a major user of REBUS data, there are no formalized communications between these two groups with CMS. The CMS representatives reported the occurrence of infrequent meetings to discuss data quality issues with UNOS or USRDS, but stated the reason for no formal communications with either organization is because they are under contract with HRSA and the National Institutes of Health, respectively, making regularly scheduled meetings inappropriate.

The lack of communication with CMS has frustrated representatives of UNOS and USRDS. The UNOS representatives reported the inability of CMS to load their transplant and wait list data into REBUS. The UNOS representatives believed regular communications could have prevented many of these problems. Representatives from the USRDS expressed frustration with learning that CMS knew of data problems, but did not share them with data users. The USRDS representatives said that they made efforts to verify the accuracy of data, and, after identifying the problems, contacted CMS only to learn that CMS was already aware of the problems.

Networks also noted communication problems and stated their desire for more formalized contact with CMS. Although CMS representatives reported that they hold quarterly conference calls and that individual Networks are welcome to participate, Network representatives seemed unaware of these calls. The Networks are looking for a forum to express their concerns with their role. For example, CMS is in the testing phase of this new data system, the Vital Information System to Improve Outcomes in Nephrology or VISION. This system will allow facilities to electronically submit all facility and patient

information, thus replacing the need for the Networks' to enter the data from the paper forms. Although CMS sees this as a way of streamlining the data entry process, Networks representatives with whom we spoke believe VISION will replace their role of editing and reconciling the data.

Staff within the CMS acknowledged the validity of the Networks' complaints regarding communication, and stated that the group is working to improve communication. The CMS representatives reported they are in the process of assembling several workgroups with representatives from CMS, both headquarters and regional offices, and the ESRD Networks to encourage communication. The workgroups are being formed to "address current ESRD concerns and functionality of the Standard Information Management System software application" and to ". . . improve communication between CMS and the Networks regarding reporting requirements and clarification of policy issues."

# RECOMMENDATIONS

The CMS is well aware of problems within REBUS. The CMS has expended considerable effort maintaining and updating REBUS, and steps have been underway for some time to develop a replacement system (REMIS). Nevertheless, considering the history of data problems with REBUS and the various delays that have stalled the implementation of REMIS, we recommend that CMS:

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## Develop a Strategic Plan for Addressing ESRD Data Management

The strategic plan should build on CMS's current efforts to address data shortcomings. At a minimum, the plan should address the following four areas:

▶ ***Short and Long-Term Targets***

Data providers and end users are currently experiencing problems with REBUS. The CMS's strategic plan should address target dates for updating REBUS and restoring out-of-date datasets. In addition, the plan should establish realistic target dates for the completion of REMIS and the transfer of data from REBUS into REMIS. This plan should be communicated to both data providers and end users for use in their planning.

▶ ***Data Needs***

Although CMS describes REBUS as “. . . a mission critical system . . .” problems with the timeliness, completeness, and accuracy of some datasets within REBUS raise questions as to the importance of these datasets to the operation of CMS's ESRD program. The CMS should assess internal data needs and the needs of external data users to determine the appropriateness of CMS maintaining these datasets, whether in REBUS or in REMIS.

▶ ***Efficiency of Data Distribution***

Within the constraints of the Privacy Act and other applicable laws and regulations, CMS should reassess where and how ESRD data users obtain needed data. End users have expressed a preference for receiving data directly from the source, largely because of problems with REBUS. If CMS decides that it is most appropriate for end users to obtain data directly from the source, it should factor this decision when determining which datasets should be maintained within REBUS and/or REMIS. The CMS also should work with end users to develop the most efficient methods for obtaining data from the providers. These efforts should improve overall efficiency and reduce duplication of effort and increased costs.

▶ ***On-going Communication***

All groups who interact with REBUS suggested they would benefit from improved communication with CMS, and CMS has agreed. The CMS should establish regular, periodic meetings to discuss ESRD data management issues with internal and external data providers and end users.

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## **Coordinate with the Social Security Administration to Address Errors in Basic Beneficiary Information**

Efforts to correct errors in the Identification dataset are not effective as information within this dataset is overwritten nightly using information received from SSA. The SSA data will overwrite any corrections made to the dataset. According to CMS representatives, SSA has given low priority to correcting errors in ESRD beneficiary records. The CMS may want to consider holding high-level meetings with SSA to develop a mutually acceptable solution for addressing problems with basic beneficiary information.

## AGENCY COMMENTS

In its written response to our report, CMS acknowledged limitations with REBUS and concurred with our recommendations. The CMS highlighted various actions taken since completion of our draft report, including devising short and long-term strategic plans, initiating meetings with data providers and users, and reaching agreements to reduce or eliminate non-essential data transfers. In addition, CMS is now encouraging various data users to seek information directly from the source rather than relying on CMS's system.

We made minor changes to reflect technical comments received from CMS. The full text of CMS's comments are included in Appendix A.



*Administrator*

Washington, DC 20201

**DATE:** DEC 21 2001  
**TO:** Janet Rehnquist  
Inspector General  
**FROM:** Thomas A. Scully  
Administrator

**SUBJECT:** Office of Inspector General (OIG) Draft Report: *Problems Pervade the Renal Beneficiary and Utilization System (REBUS) (OEI-07-01-00250)*

Thank you for the opportunity to review and comment on the above-referenced draft report, which examines problems resulting in duplication of effort, delays, and program vulnerabilities in end-stage renal disease (ESRD) data management. The Centers for Medicare & Medicaid Services (CMS) acknowledges the many limitations of the existing REBUS operational environment. We have expended considerable resources to address these shortcomings and have developed a short- and long-term strategy to correct these problems. We are confident that our efforts have made considerable progress since your work on this OIG draft report was completed. We will continue in our efforts to keep REBUS current and accurate as we redesign ESRD systems to better meet our business challenges.

We appreciate the effort that went into this report and the opportunity to comment on the issues it raises. Our detailed comments on the OIG recommendations follow.

### **OIG Recommendation**

The CMS should develop a strategic plan for addressing ESRD data management. The strategic plan should build on CMS' s current efforts to address data shortcomings. At a minimum, the plan should address the following four areas: 1) short- and long-term targets; 2) data needs; 3) efficiency of data distribution; and 4) ongoing communication.

### **CMS Response**

#### **Short- and Long- Term Targets**

The CMS understands the need for a strategic plan to address the shortcomings outlined in the above-referenced report and has begun the development of this plan. As part of the plan, CMS will adopt an integrated approach to ESRD systems development. Currently, the REBUS and Standard Information Management System (SIMS) are independent, stand alone data repositories that communicate with each other via a complicated file exchange. Phase I of the Renal Management Information System (REMIS) redesign will concentrate on integrating these

systems. A detailed validation of the current REBUS and SIMS is currently underway. In Phase I, CMS will cleanse the current REBUS and SIMS data and integrate these data into one common ESRD data repository (warehouse). We are also implementing the Vital Information System for Improved Outcomes in Nephrology (VISION) as a standard, front-end forms collection tool for ESRD dialysis centers as part of our Phase I effort. VISION will greatly improve the quality of our ESRD data warehouse. Phase I of the REMIS redesign is scheduled for completion in July 2002. Phase II will commence in the fall of 2002 and will concentrate on identification of existing and new requirements. These additional user requirements will be incorporated into logical quarterly releases of VISION/SIMS/REMIS software. Strict configuration management, testing procedures, and protocols will be used in this new operational paradigm to ensure integrity of data and software.

### **Data Needs and Improved Efficiency of Data Distribution**

The CMS is addressing its internal data needs for the ESRD program, as well as the needs of external customers for ESRD data, as part of its integrated ESRD systems effort. This effort encompasses the following:

#### **Improved Techniques for Data Transmission and Receipt**

As recently as October 2000, obsolete technology affected essentially all of the processes that supplied REBUS with data essential to its business purpose. Even in cases where improved technology was available to the data source organizations, REBUS accepted data only in the modes and formats used when REBUS was developed. Since November 2000, REBUS/REMIS developers have been working toward methods requiring less workpower.

#### **Patient Status Information**

In November 2001, REBUS began drawing information from the ESRD networks' SIMS, whose central server is located in CMS headquarters. (Previously, the ESRD networks had been required to extract information from the PC-based SIMS system and prepare 18 separate sequential datasets on the CMS mainframe.)

#### **Transplant Information**

Also in November 2001, the data prepared by the United Network for Organ Sharing (UNOS) for use in REBUS have drastically reduced in volume, in frequency, and in workpower required for processing. Additional improvements are planned for Phase II of REMIS.

#### **Consultation with Users of REBUS/REMIS Data**

See Ongoing Communication below. REBUS/REMIS system representatives attend ongoing meetings focusing on the data needs of customers. REBUS/REMIS managers will present information on the integrated ESRD system effort to these audiences.

### **Consultation with Providers of Data**

REBUS/REMIS is "fed" by transplant and dialysis data from CMS's systems, current ESRD patient status data from SIMS, and transplant data from UNOS.

The CMS initiated regular monthly coordination meetings with UNOS and the Health Resources and Services Administration's (HRSA) representatives on November 7. That first conference achieved several agreements:

- The UNOS may discontinue weekly files for CMS -- monthly files suffice for CMS's needs.
- The CMS does not need non-ESRD data from UNOS.
- The CMS will not house UNOS's data to meet United States Renal Data System's (USRDS) needs. (USRDS will be encouraged to "go to the source" of the data; HRSA has no objection to this approach.)
- Pending consultation with the ESRD networks, CMS will no longer house transplant wait list data, since the networks can obtain them from UNOS (and many of them have done so). The networks will be encouraged to "go to the source" of the data.
- After confirming specifications, CMS will reinstate REBUS reports that provide information requested by UNOS (including information on transplant providers, deaths, and transplants not recorded by UNOS).

The CMS has met regularly with SIMS developers and stakeholders since the start of the SIMS development effort (frequently through teleconferencing). In recent months, as part of the integrated ESRD systems effort, in-person meetings have been held to:

- plan the integration of SIMS data into REMIS; and
- plan the integration of the VISION system with REMIS and SIMS.

The integrated ESRD systems effort will result in the use of SIMS data as the "gold standard" for current ESRD patient status.

### **Timeliness, Completion, and Accuracy**

Each dataset used by REBUS is under evaluation as part of the migration to REMIS. This evaluation process, known as Data Quality Assurance (DQA), assesses each field within each REBUS dataset for compliance with the documented standards ("metadata," roughly speaking) for that field. While there are no plans to add new functionality to REBUS, the DQA findings identify REBUS data that are no longer usable and help determine the appropriateness of maintaining datasets or their individual fields in REBUS/REMIS. This approach allows CMS to focus more narrowly on information essential to the REBUS/REMIS business purpose.

## **Phased Approach**

Under the integrated ESRD systems effort, REBUS functionality will be transferred to REMIS. Phase I of REMIS calls for the new Oracle-based system to "do what REBUS does" with certain exceptions: 1) any processing errors found will be corrected; 2) any unnecessary data or functionality will be dropped; and 3) the existing multi-platform feed of patient status information from SIMS to REBUS will be replaced by read access to SIMS tables by REMIS. (Acquisition activities to strengthen the SIMS hardware platform have been initiated.) The resulting system will conform to applicable CMS standards and reasonable expectations for modern database application systems.

Phase II will see a more thorough analysis of data needs, with the expectation of efficiency, timeliness, reporting, and reliability improvements. For example, Phase I of REMIS is expected to use essentially the same UNOS data as REBUS uses (although unnecessary elements will be dropped as a result of narrowing the focus of REBUS /REMIS to essential data). However, in Phase II, the use of UNOS data in REMIS will be fully reviewed. It is anticipated that the current process (receipt of compact discs (CDs) containing full-file copies prepared by UNOS; loading of data from CD to mainframe; unzipping of data on mainframe; use of mainframe Statistical Analysis Software to prepare inputs to REBUS; adding records to the REBUS Model 204 database files via FASTLOAD) will be replaced by a more efficient process, possibly involving selection of only the required data by code executing on the UNOS platform.

As part of the current REMIS phases, ESRD facilities will be able to use VISION to transmit forms electronically to CMS. Information transmitted via VISION will become part of the SIMS database. The SIMS data will in turn be treated as a part of REMIS; i.e., SIMS patient data will not be copied into REMIS, but will be read from SIMS.

### **Additional activities have been instituted to make the current REBUS system more current and accurate during the transition to the new REMIS environment.**

The OIG report states that, "Data sets within the Renal Beneficiary and Utilization System are out-of-date, incomplete, and inaccurate" and that "problems existed with 9 of the 12 REBUS datasets in the past 12 months." That statement is somewhat misleading. Two of those datasets, the Social Security Administration's (SSA) district office file and the waitlist file, in no way impact the REBUS business function. As a result of our review of the appropriateness of maintaining the various data stores in REMIS, we have determined not to maintain these two. We are testing new matching and analysis routines in order to better take advantage of the event data in SIMS and more accurately update the patient status records in REBUS. We will be loading data directly from the SIMS central repository on a regular basis. These improvements were implemented in early December 2001. We are working closely with the networks to improve the feedback that we give to them as a result of these regular census updates. We will also soon be pulling the monthly medical evidence and death notice accretions directly from the SIMS central repository, rather than have each network transmit those files to the CMS mainframe.

The table below shows the current status of REBUS datasets and is an update to the same table on page 8 of the OIG draft report.

**Table 2: REBUS Dataset Status**

<b>Dataset</b>	<b>Description</b>	<b>Status</b>	<b>Plans for updating</b>
<b>Death Notice</b>	Date, place, and cause of death	Current	N/A
<b>Facility Certification</b>	Annual provider-specific treatment and transplant data	Current	N/A
<b>Identification</b>	Basic beneficiary information, entitlement, and ESRD termination data	99.9 Percent Current	Dependent on other datasets
<b>Inpatient Stay</b>	Hospital stay dates, provider number, surgery information	Current	N/A
<b>Medical Evidence</b>	Medical conditions, lab results	Current	N/A
<b>Method Selection</b>	ESRD payment method chosen by home dialysis patients	Current	N/A
<b>Patient Status</b>	Verified status, dialysis type, most recent treatment setting	Current	N/A
<b>SSA District Office</b>	Address of local SSA offices	Not Current	No plans to maintain/no longer review
<b>Transplant</b>	Date of transplant, organ donor data	Current	N/A
<b>Transplant Follow-up</b>	Tracks status of beneficiary transplant	Current	N/A
<b>Quarterly Dialysis</b>	Aggregated information for all dialysis claims in quarter	Current	N/ A
<b>Wait List</b>	Potential kidney transplant recipients awaiting transplant	Not Current	No plans to maintain/no longer review

**Ongoing Communication**

The CMS ESRD software development staff currently communicates with several of its data users and partners in a variety of ways.

**Annual Managed Care Enrollment and Payment Conference**

The Annual Managed Care Enrollment and Payment Conference serves to assist the managed care contractors in their understanding of CMS' s regulations, policies, and program developments that affect the operation of managed care enrollment and payment processes.

The ESRD and other similar workshops are conducted to enhance communication and address concerns of managed care organizations regarding ESRD data validation processes.

### **SIMS/REMIS Task Groups**

The CMS has created a new task group structure, comprised of CMS and network staff, in order to address current ESRD concerns and functionality of the SIMS and REMIS software applications. This structure will improve communication between CMS and the networks regarding reporting requirements and clarification of policy issues. The SIMS/REMIS task groups will consist of a body of individuals tasked to perform set functions such as identifying a need, specifying the functionality needed in SIMS and REMIS, and finally testing each new process to ensure it works properly and meets all required needs. The groups will have a co-chair from CMS and a co-chair from the ESRD networks. The CMS believes it essential that the task groups be populated with network and CMS staff who are knowledgeable about the topic and who can commit the time necessary to do the work.

### **WebEx Meeting Center**

To facilitate communication between application developers, task groups, and CMS staff, a new technology called WebEx Meeting Center will be utilized. WebEx is a service that enables the easy sharing of information on the Internet (i.e., the Web) through interactive online meetings.

Through WebEx the user can:

- Give any presentation to anyone, anywhere;
- Demonstrate software, live;
- Allow anyone in the meeting to view, annotate, and edit any document electronically; .
- Share an application on your system or share the entire desktop;
- Use remote control to provide support on the Web;
- Take meeting participants on a Web tour;
- Integrate teleconferencing into your meeting; and
- Add video to personalize your meeting.

Workgroups can collaborate on any project, at any time, from anywhere; e.g., from sharing presentations to sharing any type of document, to Web tours, to full application and desktop remote control, and provide all the capabilities necessary to support real-time meetings on the Web.

### **OIG Recommendation**

The CMS should coordinate with SSA to address errors in basic beneficiary information.

### **CMS Response**

CMS has worked diligently with SSA to try and resolve disagreements between our databases. More work needs to be done on this and we will continue to work with SSA to resolve these issues.

The first is that identification data on the SSA Numerical Identification (NUMIDENT) record may disagree with data on the SSA Master Beneficiary Record (MBR) that updates the CMS Enrollment Database (EDB). The second is that SSA may have documentation that contradicts information that providers of CMS data (the ESRD networks) insist is correct. Below follows a brief history.

In 1995, when REBUS was designed, a mechanism was created to enter discrepant patient identifier records (name, claim number, date of birth, and sex) in REBUS. The CMS would generate a list on an as-needed basis and forward it to SSA for investigation and correction. In 1996, we realized the data that were forwarded to SSA for update were not being changed. The CMS contacted the Office of Disability, SSA, and was told the list may be forwarded to the SSA field offices for resolution. The CMS again contacted SSA concerning the outstanding data correction requests. The CMS was informed that its request would be transferred to an area responsible for data corrections. In 1997, SSA notified CMS that it reviewed the lists and found written documentation which confirmed that the SSA record showed the correct date of birth, which was different from what the beneficiary reported to the network. According to SSA, its NUMIDENT file confirms the beneficiary's name and date of birth. The CMS has noted data discrepancies between the NUMIDENT and SSA's MBR, which updates CMS's EDB. In these instances and with surname changes, SSA suggested that the beneficiary contact his or her local SSA field office. The SSA also noted that data corrections are a low workload priority unless these changes have a direct effect on the beneficiary's benefits. The SSA's average workload backlog is 6 months.

In addition to the above-described situation, we have also been attempting for the past year to coordinate with SSA regarding the VISION project and our ability to send, and SSA's willingness to receive, electronic ESRD form data in place of the paper forms it receives today. As with the errors, we have been unsuccessful in obtaining SSA's firm commitment to receive data electronically.

In our discussions with OIG during the exit conference held for discussing this draft report, we strongly suggested that OIG include more detail regarding our efforts with SSA, which we again reiterate. We also suggest that this report in final form be sent to SSA.

Again, we appreciate the effort that went into this report and the opportunity to review and comment on the issues it raises.